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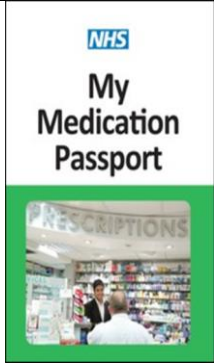
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Patient perspectives on the use of 'My Medication Passport'

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2. Susan Barber, Improvement Science Manager, NIHR CLAHRC NWL
3. Emily Ward, Quality Improvement Pharmacist, Chelsea and Westminster Hospital and NIHR CLAHRC NWL
4. Fran Husson, Patient Representative, NIHR CLAHRC NWL and Imperial College Healthcare NHS Trust
5. Margaret Turley, Patient Representative, NIHR CLAHRC NWL

Introduction

Commented [BJ1]: Alison –we wondered about this as a summary box for the article – please use or ignore as you see fit

My Medication Passport	
<p>My Medication Passport (MMP) is a passport size booklet. It features:</p> <ul style="list-style-type: none">• A list of the patient's current medicines• A List of medicines that the patient cannot take and reasons why• Compliance aids being used• Notes about changes to medicines• Allergies• Relevant information about the patient's GP, community pharmacist, hospital and other clinicians• Blank pages to make notes, for example regular clinics (e.g., heart, diabetes, respiratory)• Relevant illnesses; vaccinations; screening	

My Medication Passport (MMP) is a passport sized booklet designed by older patients to help them manage their medicines and promote effective and up-to-date communication between patients and service providers. It is updated by the patient or carer and accompanies them along the entirety of the patient journey. Patients are often asked the same questions by multiple clinicians and may not always recall the relevant information. MMP can support the safe transition of care, particularly when other records are not up to date or available to every clinician. Moreover, MMP can also aid patients and their carers to open a dialogue about medicines, health beliefs and other matters that are important to them.^{1,2}

Since its launch in 2012, more than 125,000 MMPs have been ordered by pharmacies, hospitals, charities, GP practices, nursing homes, libraries and by patients and carers across the British Isles and beyond. Additionally, over 5,000 iPhone and 4,263 android MMP apps have been downloaded, in at least 37 different countries worldwide.

Background

Originally designed with older people in mind, MMP is demonstrating usefulness for people of all ages who take multiple medicines. The number of people living with one or more long-term condition is rising^{3,4} along with the average number of medicines prescribed to an individual.⁵ Given the likelihood of multiple care providers, MMP has proved invaluable to users negotiating what are often complex care pathways, regardless of age.²

Older patients have driven the development of MMP from inception and continue to champion its use. Following an initial focus group, development of the passport was led by patient and public representatives through discussions at a project steering group. Working drafts were then referred to a local reader group. The development team included patients, carers and clinicians from a range of care sectors.

The purpose of this article is to share insights from two older users at the fore-front of the development of MMP, about why it has been an important journey for them, how they use their passports and what messages they have for other potential users.

Participants

The interview was conducted by phone on 28th September 2015. The interviewers were BJ, EW and SB. The interviewees were FH and MT.

The interview

Could you describe MMP in your own words Fran?

Simple. At first glance, it is designed to capture the key medical facts which enable the owner to present information about themselves, to any clinician in any care setting and provide facts easily and promptly. These facts might include: identity, NHS and hospital numbers, allergies and adverse drug reactions/side effects, aids and devices used, current medication regimen, space for recording vaccinations, screenings, other information. Nothing very difficult, nothing very revolutionary – but it's so useful to have it all listed in one place!

What does it feel like when you start to use MMP?

First of all, when first given a booklet, the new user needs to start thinking about the information s/he will enter in it. In most cases, a new psychological reflective process has to take place. ...patients, who because of complex long term conditions and multi-morbidities....often face a few moments of hesitation when considering having to start using MMP. As for online multi-access and data sharing across all health and social care providers, this may happen one day but we aren't there yet. The booklet will also benefit from what is called "the affordances" of paper: the owner with the use of the ubiquitous post-it note and/or printed labels can customize and update MMP at will and at any time. Customization is one of the most important facets of MMP.

Can you tell us about when MMP has proved its worth in your personal circumstances?

A good example of this is that I take more ownership of my medicines, in the sense of being much more aware of what exactly I need to take every day in relation to specific indications; of when I need to renew prescription medicines; of the need for prescribers to also see vitamins and supplements I have decided, accurately or not, to purchase and self-administer. The booklet is the lynchpin for consistency, constant updating and reviewing.

Another example is that MMP supports me to be active, in the sense that I take responsibility for what goes in to the booklet, and in the sense that I can use it to support conversations that I have with clinicians, and to show other service users. Activation is really the name of the game! Admittedly there are other tools and apps. As far as I am concerned, the small booklet has no competition because its use is instant, unlike having to use my laptop or tablet which of course have other beneficial uses to manage my health care. The booklet is basically a piece of paper and a pencil and can be used by everyone who wishes to and finds it of use.

Can you give us an example of what health professionals have said about the usefulness of your MMP?

Community pharmacists that I visit have on separate occasions used MMP to change my selection of over-the-counter medicines. For example, I was stopped from buying Lemsip® because of the phenylephrine hydrochloride which increases blood pressure. And of course it is wonderful to be able to present a comprehensive medical picture of oneself with any healthcare professional whether dentist, optician, physiotherapist – whoever one needs to interact with.

Do you have any tips for other older people who take multiple medicines?

My first tip would be to have a good medication review to ensure they fully understand why each medicine has been prescribed, for how long, the importance of right dose at the right time. Then they can record the information in their MMP and keep it up to date when medicines are changed or stopped.

What's your experience of MMP, Margaret?

My son is able to go to the epilepsy clinic on his own, as everything is written down.... It gives Brian independence, as it has done for lots of people! Before MMP he was not able/did not want to go on days out with friends, he was afraid he may have a seizure.. now he goes everywhere. It's brilliant! Yes we have had episodes .. where he has been taken to a strange hospital, this no longer worries him as he has MMP! The Hospitals have liked it, as have the front line staff.

In addition, I know of elderly people who thought they were too old to go abroad, along came the MMP it gave them a new lease of life, now they travel once again.

I know that you are both active in your community and that you have considerable insight into who else is using MMP. Fran, can you tell us a little about that?

Yes, both of us have championed the use of MMP; from getting people involved in designing and developing it, to understanding how useful it is and using it. For a number of years now we have actively promoted MMP, given introductory talks about it, and made people aware of its many uses. It has been both inspiring and informative to have a window into the lives of others who have found this fairly simple booklet so useful.

A selection of places and groups where service users and providers have promoted the use of MMP
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Libraries Health fairs hosted by local health authorities Health Education England training workshops Local care and residential homes Faith groups Emergency services [paramedics] Dental workshops High Street pharmacist distribution Market stall chats and distributions at various hospital foyer and outpatient clinics Ongoing activity with Age UK, including Radio Interview, Open Age, the Advocacy Project. Women's Institute

Clinicians may fear that a patient-completed MMP may not be accurate and may therefore increase risk. What do you think?

One senior pharmacist always made it clear that even if patients, or carers made a mistake in entering a medication dose, what really mattered to the health care professional treating the patient was the name of the medication, which would provide some indication of conditions and illnesses.

Another pharmacist pointed out that medicines reconciliation should involve the use of two sources of information and that MMP can count as one of those when needed (for example on admission to hospital).

I've heard other health care professionals say things like: "Not only is it a great tool for me to understand and reconcile all the medications a patient may be using, but I do not feel like I am subjecting elderly patients to an interrogation at each consultation" "It does not matter to me if the patient has written down the wrong dosage, what really matters is for me to know all the medications, "over-the-counter medicines" and supplements they are taking, and to understand how these have been prescribed in the first place".... ". Another doctor recalled correcting a patient's Summary Care Record, with the help of the patient and her MMP.

What filters out is the autonomy MMP affords to elderly patients.

Elderly patients ALL have deficits, whether related to lifelong learning, disabilities, chronic conditions and multi-morbidities resulting from illnesses or accidents, and of course cognitive decline linked to growing old.

In my experience, having MMP is the only affirmation tool that truly helps in this situation. It very much supports us to say and to show "This is me. I am a person. I am going to place my MMP on your desk and I expect you to use it!"

And Barry, you've been doing some work with MMP too. Tell us about that?

The work that I've been involved in is at a professional level, and also a personal one. As a pharmacist I've worked for some time with a team to optimise medicines use, improve medication review and ensure the availability of MMP among elderly rehabilitation patients who attend the Chelsea and Westminster Hospital.

MMP has also been invaluable as I care for Alexander, my 10-year-old son with Down's syndrome, severe disabilities and long-term medical conditions.⁶ He attends a special school and has a number of co-morbidities. He is supported regularly by general practice, the school nurse, ear nose and throat (ENT) specialists, general and community paediatrics, dietetics, specialist dentistry and ophthalmology. Medicines are a key part of his treatment, along with physiotherapy, speech and occupational therapy.

As a pharmacist and a carer, I know that in the UK there is no single, complete record of medications for individual patients that can be guaranteed for patients regardless of age. There is a risk of interacting medicines being prescribed by clinicians oblivious to other medicines being taken by the patient. Patients and carers are often relied on to recall the complete medication list and this can be challenging given multiple and potentially stressful appointments. During appointments in community and hospital settings the MMP has really helped us as carers and in particular it takes pressure off of us having to detail all of Alexander's medicines over and over again, and it has reduced the risk of error in recalling those details when necessary. We understand that this concurs with the experience of older users of MMP.

Summary:

We hope that Fran and Margaret's positive experience in developing, using and sharing MMP provides helpful insights. In addition, we know that it is used across a spectrum of ages among people who take multiple medicines, who may live with one or more long-term condition and who may see a variety of clinicians in different contexts. Barry has pointed out that paediatric users of MMP may benefit in the same way as some older patients who were reported as not being interested in their own care, but were 'activated' by the MMP. MMP can change such individuals' perspectives and provide a tangible resource to initiate conversations with their health care professionals that may hitherto not have been considered.⁷ Diabetes and asthma are two long-term conditions where such a passport might help encourage younger patients in supporting self-care.¹

Key questions not yet explored outside of a single case-study include: how might a variety of older people and their carers use MMP? Does MMP support patients and/or carers to be more actively involved in their own health care and how? Does it encourage a different dialogue between patient, carer and health care professional and does it ease communications between them and how? Where health care professionals encourage MMP use, what do they anticipate will be the outcome? Are there improvements or challenges that have not yet been thought about?

NIHR CLAHRC Northwest London are currently supporting the distribution of MMP and encouraging more evaluation of its use, to better understand of MMP, how it is used, the impact, what limitations users report and how it is perceived by clinicians. More case studies of different types of users and of their use of MMP would be invaluable to enhance our understanding.

Note: Following this interview, Margaret's son Brian Turley, a keen advocate of MMP and for people with learning disabilities, died in February 2016 aged 47. He is sadly missed by his family and all who knew him.

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